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05 December 2017

Version of attached file:

Published Version

Peer-review status of attached file:

Peer-reviewed

Citation for published item:

McMurray, R. and Cheater, M. and Weighall, A. and Nelson, C. and Schweiger, M. and Mukherjee, S. (2004) 'Managing controversy through consultation : a qualitative study of communication and trust around MMR vaccination decisions.', *British journal of general practice.*, 54 (504). pp. 520-525.

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Managing controversy through consultation: a qualitative study of communication and trust around MMR vaccination decisions

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SUMMARY

Background: Controversy over the measles, mumps, and rubella (MMR) vaccine has reduced uptake, raising concerns of a future disease epidemic.

Aims: To explore parents' accounts of decision making relating to the MMR vaccine controversy, identifying uptake determinants and education needs.

Design of study: Qualitative interviews analysed using the 'framework' approach.

Setting: Five general practices in the Leeds area, 2002–2003.

Method: Sixty-nine interviews conducted with parents of children aged between 4 and 5 years, and 12 interviews with primary care practitioners, managers and immunisation coordinators serving participating sites. Participants were interviewed one-to-one in a place of their choice.

Results: The vaccination decision is primarily a function of parental assessments of the relative acceptability and likelihood of possible outcomes. For most parents the evidence of science and medicine plays little role in the decision. Although local general practitioners and health visitors are trusted information sources, the influence of primary care providers on the vaccination decision is limited by concerns over consultation legitimacy, discussion opportunity, and perceptions of financial and political partiality. Parents and practitioners identify a need for new approaches to support decisions and learning when faced with this and similar healthcare controversies. These include new collaborative approaches to information exchange designed to transform rather than supplant existing parent knowledge as part of an ongoing learning process.

Conclusion: The study identified new ways in which parents and practitioners need to be supported in order to increase understanding of medical science and secure more informed decisions in the face of health controversy.

Keywords: health services; managed care; measles-mumps-rubella vaccine; MMR vaccine; trust; vaccination.

Introduction

IN the United Kingdom (UK), controversy over the safety of the combined measles, mumps, and rubella (MMR) vaccination has led to growing concern among practitioners and parents. Despite overwhelming research evidence against a causal link between MMR vaccination and autism and bowel disorders,^{1–6} media coverage of the issue has 'succeeded in denting parents' confidence in childhood immunisation'⁷ leading to fears of future measles, mumps, and rubella epidemics.⁸

There is agreement that primary care professionals, particularly general practitioners (GPs) and health visitors, have a central role in educating parents on the safety and effectiveness of the MMR vaccine.^{6,9–15} This role is broadly conceived in terms of communicating disease information to parents confronted with the challenge of accessing and interpreting medical data. Difficulties faced by parents in these respects tend to be conceptualised in terms of a cognitive deficit model of understanding and learning. From this traditional perspective, ignorance on the part of the public is seen (often incorrectly) as a technical problem in need of, and amenable to, remedy.¹⁶

In seeking to prescribe such a remedy, work undertaken by McGuire indicates that statements emphasising the seriousness of the diseases are most likely to influence a vaccination decision, whereas appeals to social responsibility, a child's right to be protected, the value of prevention, or reference to the actions of practitioners in relation to their own children have little impact.¹⁷ More broadly, a recent review of risk presentation across a range of clinical settings acknowledges that patients often desire more information than is provided, require two-way communication of risk in which there is an exchange of information and opinion between patients and practitioners, may benefit from the inclusion of decision aids, and need balanced information that has not been biased by practitioner attempts to frame information in such a way as to achieve predetermined goals.¹⁸ Indeed, Evans *et al* identify issues of practitioner bias as a particular concern among parents considering MMR vaccination.¹⁵

Despite a growing understanding of what information should be communicated to parents, education initiatives have met with limited success in the face of persistent — even disproportionate — controversy.¹⁹ Concerted effort among practitioners locally, policy makers nationally, and bodies such as the World Health Organisation internationally, have failed to convince many parents of MMR vaccine safety. The result has been a decline in uptake in the UK, with

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Submitted: 13 November 2003; Editor's response: 2 March 2004; final acceptance: 28 April 2004.

© British Journal of General Practice, 2004, 54, 520–525.

HOW THIS FITS IN*What do we know?*

Continuing controversy has led to parental concern and confusion over the safety of the measles, mumps, and rubella vaccine, leading to a decline in uptake and fear of disease epidemic. Previous research suggests that primary care practitioners have a key role in educating parents as to the safety and effectiveness of the vaccine, although recent campaigns in the United Kingdom have had limited influence.

What does this paper add?

To combat safety concerns and health scares, practitioners must be seen as expert interpreters of risk information, capable of linking medical data on best practice to parents' existing frames of reference, so as to transform understanding of decisions and facilitate informed choice. Practitioners can only guide parents through conflicting evidence as part of a facilitated learning process where they are seen as a trusted impartial source. Recovery of this position is contingent on removing target payments, lessening restrictions on time, and developing skills for the assessment of prior knowledge and management of targeted information exchange.

immunisation rates at first dose falling from a peak at 92% in 1995, to 84% in 2001–2002, with the average at second dose standing at 74%.²⁰

The study reported here examines why practitioner attempts to educate parents have met with only partial success. It aims to shed new light on those factors that underpin parental perceptions of risk in relation to the MMR controversy, with particular attention to the point of lowest uptake, namely, second dose. Finally, it seeks to pinpoint the primary determinants of vaccination choice, and, in a departure from previous work, analyse findings in light of the literature on public understanding of science, to identify the developments required to support parent–practitioner attempts to arrive at informed decisions on health interventions and risks.

Methods

The research was conducted over 16 months beginning in January 2002. Leeds Research Ethics Committee approved the study, which took place in five general practices. Practices were purposely sampled to allow for diversity in the size, location and level of deprivation in the populations served (Table 1).

Practices sent letters to all parents of children born within 1 year, ending 31 March 1998, explaining the aims, uses and researchers associated with the study. The letters invited parents to contact the team by telephone or freepost should they wish to participate in the research, and were signed by the child's GP. Following receipt of an expression of interest, a time for interview at the parent's own home or place of work was arranged. Interviews were designed to explore parental experience and needs in relation to information and decision support at the point of lowest uptake, namely MMR vaccine second dose.

Practitioner interviews were also conducted (reported elsewhere).²¹ These were designed to provide contextual

Table 1. Practice deprivation and location status.

Practice	Deprivation status ^a	Location
A	High	Inner city
B	High	Inner city
C	Moderate	Urban
D	Moderate	Urban
E	Low	Semi-rural

^aCategories defined according to low income scheme index prescribing data.

data describing the process of vaccine administration within each practice, including variations in approaches and roles. As such, they provided an account of procedures and practice within which parental accounts could be located, and against which comparisons could be made.

All interviews were semi-structured to the extent that the ordering of questions could be changed to reflect the flow of conversation while allowing new issues to be introduced. To reduce the possibility of socially desirable response, interviews were conducted in parents' homes by three non-clinical team members. Pre-study piloting and continuous transcript comparison were used to ensure equivalence in subject topic coverage and questioning approach across the sample.

Full transcripts of interviews were analysed using a variation of the well-established 'framework' approach.²² Sub-samples of transcripts were reviewed by the authors to identify key themes for data coding. Codes were then defined and validated through discussion among the research team. These were then applied to the data using the visual qualitative data processing package QSR Nvivo. Overarching themes and 'one-off' or 'deviant' cases were identified in order to understand the research findings and report them in a meaningful, yet concise, way.

Results

Sixty-nine interviews were conducted with parents, 65 of whom were mothers. The average age of parents participating in the study was 34 years (range = 22–44 years). The mean school leaving age of participating parents was 17 years. Sixty-four per cent of those interviewed were in full- or part-time paid employment. Eighty-seven per cent were married or living with a partner, 6% were divorced or separated, and 7% were single. The number vaccinating at both doses was 75%, just above the average of 74% for England (Figure 1).²⁰

Over half of all children discussed were male (57%). Half came from families with two children, 36% from families with three or more children, and 12% were an only child. All children in the non-immuniser category were boys.

There were no discernible links between immunisation status and maternal age, educational status of parent, family structure, number of children or birth order. Three of the key themes to emerge from the data are presented below. These related to decision determinants, practitioner influence, and support needs.

Decision determinants

The primary determinant of vaccination decision across the

sample was prior parental experience of autistic disorders or the mumps, measles or rubella diseases. Such experience informed parents' judgements of the acceptability of (a) alternative outcomes, and (b) the perceived likelihood of a given outcome.

Parents who declined vaccination in whole or part had seen children with autism first-hand through family, friends or work, or believed their own child to be autistic (though not all cases were medically confirmed). These parents perceived that the disabling long-term impact of the disorder was far worse than the mumps, measles or rubella diseases. The diseases were seen as relatively mild, treatable and natural — something that the child would survive and even benefit from:

'I think there can be positive things about them catching measles, mumps, and rubella. They're not as serious as the government makes out ... If children get measles, mumps, and rubella it helps build up their natural immunity, and that's better than the immunity built up by vaccines.' (Practice E, parent 27e, first dose only.)

Conversely, those who agreed to immunise their child were far more likely to have experienced, or observed in relation to immediate family, the negative impact of the measles, mumps or rubella diseases in terms of acute illness or long-term impairment:

'We'd decided that whatever the risks were of having the vaccination, of possible problems, we still felt it was just better for them to have the injections than run the risk of any of the diseases. My husband is deaf in one ear and that happened, they're almost certain, after he had the measles as a child and so he felt it was far more important that they did [get vaccinated] and run a very small risk of autism.' (Practice C, parent 10c, complete vaccinator.)

'Measles, mumps, and rubella inoculation is very important to me. My husband had a brother who died when he was 1 year of age with measles encephalitis and I think one of the big problems with parents — because I've talked to people quite a lot about it — is that they don't realise how serious measles is and can be as a disease.' (Practice C, parent 12c, complete vaccinator.)

For reluctant vaccinators, who agreed to a second dose of MMR vaccine despite strong reservations, their decision was based on assessment of outcome likelihood rather than impact. Two factors encouraged assessments indicating low autism risk. First, their child did not have any problems after the first dose. Second, parents observed no evidence of autistic disorder in their immediate social sphere. This second basis for risk assessment served for some as their primary source of tangible facts:

'The final thing that clinched it was just [name of partner] and his like, sensible everyday comment, not rooted in medical history that "Well do we know anybody who's had an adverse reaction?" Because that is rooted in fact. Tangible fact that we can both hold on to. It's not a

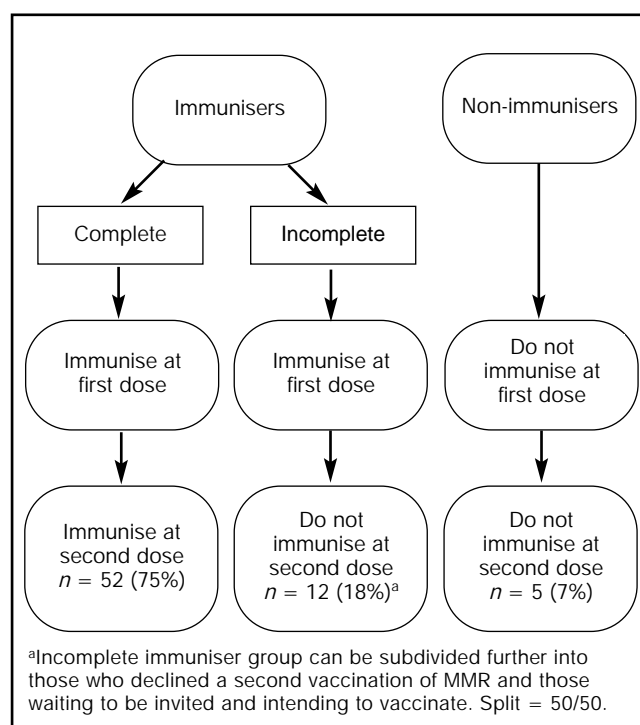


Figure 1. Vaccination status for study sample.

scientific report that we can't understand, it's actual everyday living, and the answer to that was no. And that's why, that was the point that really made me realise we were definitely going to go ahead [and vaccinate].' (Practice C, parent 9c, complete vaccinator.)

For almost all parents, assessment of disease impact and risk tended to have their basis in experiential knowledge. Vaccination decisions were based on day-to-day observation rather than the evidence of science. There were exceptions, however. Where parents, or those known to them, were employed in medical or scientific fields, they acted as informal experts capable of weighing the evidence and informing decision. Even here, though, some parents felt a need to apologise for making a rational rather than emotional response to the controversy that surrounded MMR, with one parent commenting that at some level it 'sounds awful' to be reliant on scientific information, the implication being that as a mother she should just know what is best.

Practitioner influence and limits

Beyond individual experience there were a range of factors that served to confirm, complicate and occasionally alter vaccination decision. The mass media raised concern and initiated information search. Friends and family provided a chance to share feelings and experience. GPs and health visitors provided medical input, and were most frequently cited as the best or most trusted source of information on MMR:

'The GP was very good. Very good, very clear in her advice. But not dictatorial. She just sort of presented me with the facts and with the information ... I was able then

to come away and think, "Yes". I felt at the time that it was the best advice.' (Practice E, parent 29e, complete vaccinator.)

'I'm very impressed with our GP, I think she's very good and I mostly see her for the children and she's very good with them.' (Practice C, parent 27c, first dose, awaiting second.)

'Well, you have to put your trust in doctors.' (Practice B, parent 7b, complete vaccinator.)

Despite the trust most parents espoused in their local practitioners, few cited them as decision influences. Although often reluctant to criticise their individual GP or health visitor, parents (particularly non-vaccinators) censured practitioners en masse for being too willing to toe the party line on MMR, being brain-washed by government and inevitably biased in favour of vaccination by the award of target payments:

'I've never had a problem with doctors not being willing to listen to my viewpoint, but I know that doctors and health professionals have to give the government line, so I am not expecting an unbiased discussion.' (Practice E, parent 1, non-vaccinator.)

'My problem with the advice coming from the GP is that I know that GP practices are paid a bonus for having so many patients vaccinated, so how can their advice be impartial? They are running a business at the end of the day.' (Practice E, parent 12, non-vaccinator.)

Parents were also reluctant to initiate discussion during consultation because of the rushed nature of general practice and the pressure of knowing there were other mothers queuing in the waiting room. This pressure was felt by parents and practitioners alike:

'You're conscious that there's a waiting room outside of children coming in to have the same injection and ... so you know that there's pressure on, don't you? I suppose you're at the doctor's surgery ... you're [feeling] a bit alien anyway. You just want to be in and out and you don't want to be causing a nuisance.' (Practice E, parent 20e, first dose only.)

'I'm conscious that the waiting room, the clinic at [name of practice] is a 1 hour drop-in and you have all the world sitting there. The pressure of people will make a difference.' (Practice D, practitioner 3.)

Effectiveness of consultation was further diminished where practitioners were felt to be unwilling to engage in discussion of concerns, or were dismissive, condescending or coercive. Consequently, although local practitioners were identified as the most trusted information source in principle, their actual role in decision support was hampered by questions over partiality and concerns as to acceptability or legitimacy of discussion during consultation.

Immediate support needs

Reliance on everyday knowledge coupled with insufficient contact with primary care providers served to ensure that, for a majority of parents, the decision on whether to vaccinate did not reflect an informed choice. Most parents received no information prior to appointment for second dose vaccination on the rationale, benefits and risks of immunisation or the diseases, and could not recall advice given at first dose 3 years previously. Where NHS leaflets were available, they were perceived as dull and uninformative when compared with the photographs and case histories employed by mass media. Official information was felt to bear little relation to 'real' lives, communicating little about the impact of either immunisation or the diseases. It failed to make the issue of MMR vaccination real in minds of parents and failed to communicate the importance of the issue as compared with other campaigns, such as those run by the National Society for Prevention of Cruelty to Children (NSPCC):

'I don't think they're [MMR leaflets] hard-hitting enough. I know it's not nice to see children on telly poorly and what have you, but it's like the ones for NSPCC, they make you want to cry, but they make you understand what's going on and I think that's what needs to be done about MMR. I think a lot more information of how many children have died in the past is what needs to be published, so that people can see that it is working. Otherwise there's going to be a lot of poorly children and a lot of dead, blind and deaf children about. You know, when I was at college we was handed some figures of — I think it might have been 1970 or something — of how many had died that year, how many were blind and how many was deaf, compared to 2000. And there was a dramatic difference and it was because of all the immunisation. So I think probably they could do with using that a bit more ... to prove to them [parents] that it [immunisation] is working.' (Practice D, parent 5d, complete vaccinator.)

Parents identified a number of factors likely to support informed decision on MMR vaccination. Drop-in sessions and forums at local nurseries or schools, dedicated to answering parental concerns, would offer the chance to discuss health controversies without the time constraints imposed within a practice. There was a need for written information in the days prior to a vaccination appointment, replete with case studies and pictures so that parents could relate to and reflect on available evidence. At the vaccination appointment, practitioners should offer information and seek to elicit information as a matter of course. This point was seen as necessary to overcome a tendency among practitioners (illustrated below) to take presentation at clinic as indication of informed consent, while avoiding discussion of MMR and related issues for fear of the concern that it may cause:

'... you must be happy to have it done if you've brought your child in, because if you did not want it you wouldn't bring them ... [we] don't want to put doubts in their mind. Because if there is any doubt in a parent's mind they're going to say no ... if you keep going on more maybe

you're going to scare them more and they'll say no then.'
(Practice D, practitioner 1.)

In terms of enhancing trust in any information provided, parents highlighted a need to remove target payments, for direction to other information sources, and for facilitated access to independent third parties who could be trusted to provide balanced accounts of the controversy and underlying science. As revealed in the interview extract below, parents wanted to be able to square feelings of trust in their local GP with wider concerns over partiality and a desire for independent decision support:

'... I'm not aware of any independent place where they could go and get independent advice. I don't know whether such a person exists ... I mean, I trust my GP, some people don't trust their GP. I think GPs sometimes are seen to have hidden agendas about getting the immunisation rates up ... they get to a certain target, they get more benefits and things like that. Maybe other parents aren't aware of that and necessarily won't take that on board. But yes, somewhere where I could go and get independent advice and maybe somewhere that, where I could go and sit and talk about whether they should have it [MMR vaccine] at 4 and 5 [years]. Not necessarily my GP, but somebody that, you know, can listen and advise and I can take that information away and then come to an informed decision.' (Practice B, parent 1, first dose only.)

Parents suggested that access to such information intermediaries could be incorporated into the nursery or school forums described above. This would provide an opportunity to compare the views of local practitioners and third parties, and offer parents a chance to discuss among themselves how the information provided related to existing attitudes and prevailing controversy. Finally, any information provided in general practice, clinics or more novel settings should seek to relate the risks and benefits of the intervention to the parent's local circumstances and individual child. This last point was essential if educational attempts were to be accepted as valid, meaningful and real.

Discussion

Summary of main findings in relation to existing literature

In line with existing literature, the research suggests that parents and practitioners believe that primary care providers ought to be an important source of vaccination information.^{6,9-15} However, the suggestion that providing more medical information will, in itself, increase parent understanding is not supported. Such an assumption has its basis in a cognitive deficit model of public understanding that fails to account for the fact that the use to which information is put is contingent on the social and institutional connections associated with the information source; trust in the message sender,^{23,24} and the ease with which the information can be incorporated into existing knowledge and applied to the issue at hand.¹⁶

The research presented here indicates that the vaccination message is failing to get through, not because it is not being said often enough or clearly enough (although this is an issue at second dose), but because the information provided is not being integrated into parents' pre-existing experience and understanding. In concert with the work of Layton and colleagues on the public understanding of science,¹⁶ this study indicates that there is limited utility in providing more and better information on MMR vaccine risk and disease impact unless that information is reworked and translated to a point where it has relevance for each parent within the context of their individual situation and particular level of understanding. It must take account of the 'tangible facts' (parent 9c, complete vaccinator) observed by people in their own communities, and be presented in such a way as to inform and transform the experiential information parents bring to consultation.

Strengths and limitations of this study

The qualitative methodology employed enabled an in-depth exploration of parent and practitioner perspectives on information and decision support as it relates to MMR vaccine, paying particular attention to responder definitions and interpretations. Despite drawing participants from a single health region, the study succeeded in recruiting a broad range of parents, differentiated according to age, family structure and educational attainment across five practices. In complying with the Data Protection Act (1998) and individual practice concerns, details of non-responders were not collected. It is not therefore possible to assess the impact that decisions not to participate may have had on study findings. The breakdown of participants by vaccination decision does, however, reflect the national picture,²⁰ which, when coupled with the fact that interviews pertain to a widely used two-dose vaccination schedule, ensures that findings can be generalised to similar individuals and settings on contextual and theoretical grounds.²⁵

Implications for clinical practice and future research

For health services to play a greater role in facilitating informed decision there is a need to re-organise provision to ensure more timely and engaging information transfer. Simply providing more leaflets, television campaigns and didactic verbal statements, in which medical evidence on the effectiveness and safety of the vaccine is meant to flow from the producers to consumers, is to fail to recognise the need to contextualise information with 'situation-specific knowledge, often personal to individuals'.¹⁶ Parents need to be seen as partners in a learning enterprise, rather than passive receptors or empty cognitive vessels waiting to be filled. Considered thus, the challenge becomes one of managing information exchanges so as to collaboratively transform, rather than coercively supplant, existing parent knowledge.

The solution identified by parents in this study is the creation of multi-agency forums where the views of practitioners, other parents and third parties are sought. Forums situated in nurseries or schools could serve as community

health information shops offering parents an opportunity to engage with primary care, health promotion, and scientific and social academic accounts of the MMR controversy. They would offer an opportunity to discuss different perspectives, embedding medical evidence within local contexts and individual learning accounts. This is not simply an issue of offering more. Rather, it is about the nature of information exchange and delivery. It is about delivering information through trusted sources, in time-rich contexts that enable parents to construct their own understanding, aligned with medical evidence of best practice.

In calling for the provision of multi-agency fora, parents confirm that there is growing concern over the ability of practitioners to act as impartial guides. Questions about financial incentives, government bias, restrictions on time, training needs, lack of resources, and competing claims on practitioner expertise²⁶ threaten practitioner identity as a trusted source.

At a national level, removal of target payments for vaccination may go some way to recovering practitioners' position as neutral guide.²³ Even so, support at a local level is likely to be required if parents are to fully trust and understand the information supplied.

Parents must believe that practitioners are able to provide balanced information, describing the risks and benefits of vaccination and diseases. Embedding medical information within existing experience requires that practitioners have the time to ask parents what they already know, and ascertain how best to link medical evidence to individual concerns and understanding. Information provision should, as in the best of existing practice, form part of a discussion in which practitioners are able to relate medical research to individual parents, children and communities, using visual imagery and case studies to provide vicarious experience of the impact of largely forgotten diseases. Practitioners then emerge as a neutral expert source, capable of guiding parents through conflicting evidence as part of a facilitated learning process directed at informed choice. They emerge as trusted partners in the interpretation of risk information, capable of linking data to parents' existing frames of reference and helping to transform schemata of reality.

GPs, health visitors and practice nurses are well placed to facilitate medically informed decisions by parents and patients only where there is trust in their impartiality. Such trust is central to the facilitation of medically informed decision making and learning in the face of safety concerns and healthcare crises — it is central to attempts to transform existing understanding through the tailored embedding of new knowledge. This is the case whether the issue is MMR, hormone replacement therapy, or HIV/AIDs, be it in the UK or other countries.

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Acknowledgements

We thank all those parents, practices and practitioners who contributed to the study and Bev Ibbetson and Ruth Allcroft as administrators to the project, and acknowledge the crucial support of the former Northern & Yorkshire NHS Executive as funders of the research (award RCRC/CH11SG).